

Autism Spectrum Awareness Day

Commissioner Elin Howe

April 15, 2008

It is wonderful to see so many of you here today. While this is the first time I have attended this event, it is amazing to think that less than a decade ago, Autism Spectrum Awareness Day did not exist. I commend all of you who are members of Advocates for Autism of Massachusetts (AFAM) for your tremendous advocacy and education in bringing so many citizens and elected officials together.

My job today is to give you an update on the many activities of DMR's Autism Division over the past year, including progress we have made with the new Medicaid Autism Waiver. But before I talk about how far we have come in such a short period of time, I really want to acknowledge the sobering reality that we have only just begun to understand and to address. This is what I know many members of AFAM refer to as the "tsunami" that can no longer be ignored. Autism Spectrum Disorders are no longer rare and the Center for Disease Control statistics that 1 in every 150 children is autistic is certainly borne out here in our state as we have learned through programs such as the Autism Specialty Early Intervention Program. This program serves over 1300 children under the age of 3. Additionally, we have all learned the obvious, that children with autism grow up and that their needs change as they leave the relative safety of mandated special education. Transitioning into the adult system whether it is in to DMR or other agencies is a new challenge which we must all confront together. Focusing on children is certainly the beginning whether it is through early intervention, the department of education or through the Autism Division. Ultimately, we will need to think creatively about how to serve those children as they move into adulthood as well as serving adults who are already living in our communities.

I appreciate the struggle that you, AFAM, face as a newer organization that represents a wide cross section of people on the autism spectrum including people with Asperger's. You are doing great work including your popular Family Day event at Franklin Park Zoo, as well as the efforts that went into creating today's awareness program. I understand that it is sometimes difficult to work towards a common goal when in fact there is such diversity of need. From my discussions with various representatives in the autism community, I know many of you are overwhelmed with the enormity of challenges ahead as we work to develop an appropriate array of services and supports to address these needs.

Thanks to support of parents, advocacy groups like AFAM, Mass Advocates for Children, Federation for Children with Special Needs, the Arc and many state legislators, the DMR Autism Division was created in Fiscal Year 2006 with a \$1.2 million allocation, funding was to be used "for the contracting of support services for families with autistic children through the autism division at the department of mental retardation". Through a strategic planning process involving a cross-section of

stakeholders we learned what parents are looking for in terms of services, supports and community programs. Given this, we used this first appropriation to create additional staffing capacity in the seven state funded autism support centers. The Centers work with families to provide information and referral resources and trainings. Funding also included the creation of social skills, sensory and vacation programs at each autism support center. These programs have occurred in the past three fiscal years and in this fiscal year alone will serve upwards of 1,255 children in social skills and sensory programs and approximately 1,155 families who will participate in vacation activities and community days.

We also began to address the larger community concerns of parents. One concern is early recognition of autism by general pediatricians so that families can access appropriate supports through early intervention. To this end we work with a team of developmental pediatricians to educate pediatricians on the importance of social and emotional screening as a part of the child well visits. This work continues with help from doctors at Children's, UMass Medical, Tuft's Floating Hospital for Children and Boston Medical Center.

We have also teamed up with the South Norfolk County DA's Office, South Norfolk County Arc, and the Autism Alliance of MetroWest to address parents' concerns regarding interacting with first responders who are unaware of the signs and behaviors associated with autism. The Autism Law Enforcement and Education Coalition (known as ALEC) under the direction of Bill Cannatta (a father and a firefighter) trains local police, fire, EMTs, and hospital personnel in working with individuals with autism in the event of an emergency. To date, ALEC has trained over 1,000 fire fighters and more than 1000 police, EMTs and emergency room personnel.

We have also worked with the Asperger's Association of New England on projects including the creation of an Introduction to Asperger's Booklet for families. This is now available in both English and Spanish and we have also supported the Association with their efforts to reach Hispanic families whose family members' have Asperger's in communities such as Lowell/Lawrence, Boston and Springfield.

The Division's budget has more than doubled since its inception, with \$3.2 million allocated in this year's budget. This includes funds for the Autism Home and Community Based Services Waiver. The \$2.0 million allocated for this program will serve up to 80 Medicaid eligible children. The program is designed to help children remain in their homes and actively participate with their families in their communities. The focus of the program is to offer one-to-one behavioral, social and communication-based interventions to help remediate the core symptoms of autism. The goal of these services is to help children develop basic adaptive skills, elementary verbal skills and appropriate interactive and play skills. The program will also provide related support services such as community integration activities and respite.

Once the Commonwealth received approval from the Federal Centers for Medicare and Medicaid to receive federal matching funds, the Autism Division began accepting requests to serve 80 children under the age of 9, with an autism spectrum disorder, who meet the eligibility criteria in both DMR and in Mass Health. To ensure the eligibility application process was fully accessible to families from linguistically and culturally diverse backgrounds, DMR, along with our community-based partners, made all Waiver Program Eligibility Request Forms available in multiple languages. In the ten day window when applications were accepted the Division received a total of 1,146 applications. We received 68 applications from families who have multiple children on the autism spectrum including 26 sets of twins, one set of triplets, 4 families with 3 children on the spectrum and 40 families with two children, not twins, on the spectrum. We received applications from 262 different cities, towns and villages with higher numbers in cities like Boston, Lowell, Lawrence, Fitchburg, Springfield, Worcester, New Bedford and Brockton. We received 200 requests from families for whom English is not their primary language and over 100 of these families will need translation and interpreter services. This speaks to the breath of our outreach and the demand across the Commonwealth for these types of services and supports.

Currently, the Division is processing applications to determine whether the families will be able to meet both financial eligibility—with Mass Health and clinical eligibility—with DMR.

New families who are interested in the Autism Waiver may still submit request forms to the Autism Division; however they will be treated on a first come, first served, basis and will not be considered for this initial enrollment period. To this end, we continue to receive several applications a week.

I congratulate AFAM, Mass Advocates for Children and all the Senators and Representatives whose tireless efforts promoted this important new initiative.

While I believe DMR and our many state and non-profit partners have come a great distance, we have much work ahead. I have spoken about the positive early growth of the Division, and more specifically, the Autism Waiver.

But the emergence of new services for children naturally demands that we also expand our focus to the needs of those who will one day no longer be children. The adult spectrum includes people who may require just a few hours of support each week to remain gainfully employed, while others are in need of more intensive services, including 24/7 residential services and behavioral programs.

I commit to you that I am willing to listen and to collaborate on new ways to help adults on both ends of the spectrum achieve greater independence through job training and ongoing support, and through community-based services that will allow families to rejoice in seeing their children develop and build more independent lives.

In return, I ask that you continue your work to educate others about autism and advocate for programs and supports across both the age and the spectrum for individuals with autism. Take heart in knowing that the passion and focus that resulted in the creation of the Department's Division of Autism is a flame that can only grow. Your presence here today is proof of that.

This is your State House. I hope you take advantage of this day to visit your Senators and Representatives. Being an elected official amidst a serious fiscal problem is often a thankless job, but I think it entirely appropriate, that when visiting with your senator and representative, to say that while you appreciate the demands placed upon lawmakers amidst the demands of shrinking revenues and competing interests, that the needs of families like yours should not be overlooked.

Thank you.